

It's not unusual to have a cavernoma or even a few of them. Cavernomas don't always cause you to feel poorly - lots of people have them and don't even realise.

You might need to have regular check ups with a special doctor called a neurosurgeon or neurologist, and may need to have 'scans' which are like photographs of your cavernoma. If your cavernoma is misbehaving, you might have surgery to remove it, although this is quite unusual.

You can meet and chat to other children in CaverFamilies who have cavernomas like you. You don't need to worry or be frightened about having a cavernoma. If you want to know more about cavernomas ask your parents to explain or contact the Cavernoma Community Worker.

contacts and links

Cavernoma Alliance UK website www.cavernoma.org.uk

Co-ordinator email: info@cavernoma.org.uk

Cavernoma Community Worker:
community@cavernoma.org.uk

Telephone: 01305 213876

Cavernoma Alliance UK, Suite 4,
Sommerleigh Gate, Sommerleigh Road, Dorchester
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Talking about Cavernoma with Children

CAVERFAMILIES



This booklet is aimed at children aged up to 11 years
to read with their parent or guardian



We are Caverfamilies

CaverFamilies is a branch of the Cavernoma Alliance UK, a charity which provides information, education and support.

CaverFamilies provides support for parents, children, and young people affected by cavernoma.

Supported by a cavernoma community worker, **CaverFamilies** runs an annual weekend residential for families to meet each other, talk about their experiences with the condition, and to relax, play, and have fun in a friendly environment.

This leaflet is aimed at younger children. It provides basic medical information alongside the experiences of young people living with cavernomas, their friends and families.

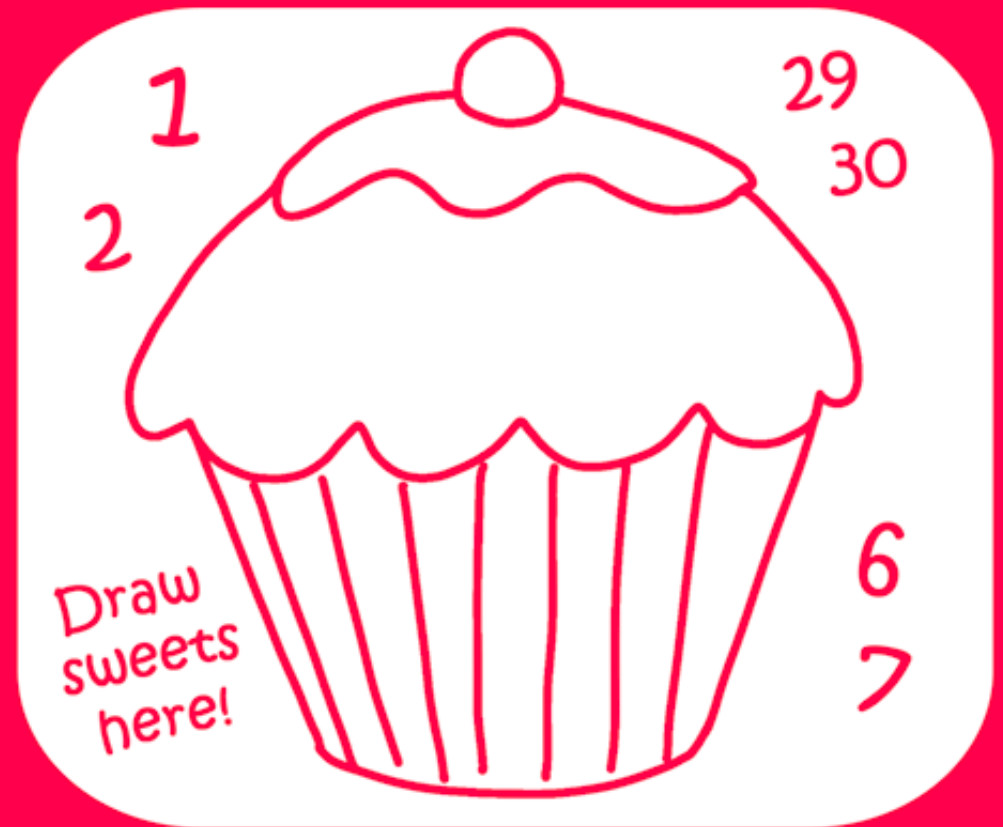
More information can be found on our website.

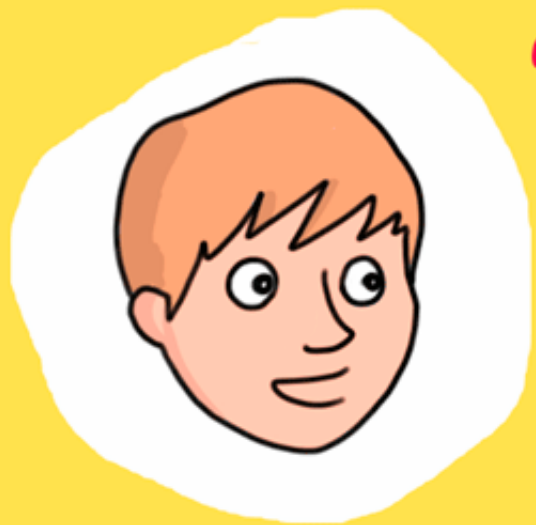


What is a Cavernoma?

A cavernoma looks like a raspberry, and is found in some people's brains.

Some people think of cavernomas like sweets in a cup cake.





Tim

aged 6

Tim has a cavernoma.

Most of the time he is like all the other children in his class, but sometimes his cavernoma is a bit poorly and he gets dizzy or has a headache.

Tim always tells his parents or his teacher, so that they can make sure he is ok.

David and Stacey



aged 8 and 5

David has cavernomas, and his sister Stacey sometimes gets worried about him, especially when he has to go into hospital for a scan.

Mum says that the scan is to make sure that the cavernomas haven't changed. His cavernomas don't usually make David feel poorly, and the doctors are working to keep David healthy.



Nikki

aged 9

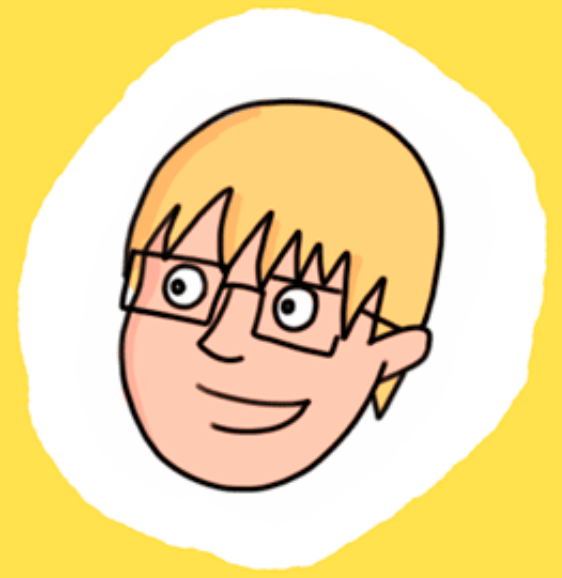
Nikki loves playing football at the weekends.

Sometimes when she's running around she gets symptoms from her cavernoma – like blurry eyesight and wobbly legs. Her friends on the football team all know about her cavernoma and they look out for her.



Sam

aged 11



Sam is the only person at his school with a cavernoma.

Last year he had a fit because of his cavernoma and now takes tablets to control it. He likes coming to CaverFamilies because it means he gets to meet other people his age with similar experiences.

